

# **Black African and black Caribbean men's understanding and experiences of prostate cancer post-treatment in England. A qualitative study.**

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## **Abstract**

**Background:** Black African and black Caribbean men are two to three times more likely to be diagnosed with prostate cancer compared with white men, and some appear to have little knowledge about prostate cancer.

**Aim:** To examine black African and black Caribbean men's experiences post prostate cancer treatment in England and to create a video to raise awareness in the African and Caribbean communities of the importance of getting tested for prostate cancer.

**Method:** Twenty black African and black Caribbean men were interviewed. A qualitative approach was employed and the data were analysed thematically.

**Findings:** This study will report on the themes of black men's knowledge and understanding of prostate cancer, misinformation, herbal remedies, information needs, and unconscious bias.

**Conclusion:** The findings showed that there is a need to raise awareness of prostate cancer in black communities to enable black men to be educated about the disease and its impact on them. Additionally, evidence based information on prostate cancer is required for the purposes of educating black men and for reducing the impact that misinformation and the use of herbal remedies have had on black men's wellbeing. In the health sector, unconscious bias should be avoided and the focus should be on inclusive and person-centred care for all regardless of one's ethnicity.

*Keywords:* Black men, African men, Caribbean men, prostate cancer, qualitative

## Introduction

In the United Kingdom [UK] over 40,000 men are diagnosed on a yearly basis with prostate cancer and around 330,000 are living with the disease in the UK [Public Health England (PHE), 2018; Prostate Cancer UK, 2017a]. In 2016, approximately 10,000 deaths were caused by prostate cancer [Public Health England, 2018] and it has been recognised as a debilitating disease for men in the UK and worldwide [World Cancer Research Fund International (WCRFI), 2016]. Men who have been treated for prostate cancer may experience a range of side effects, such as incontinence, impotence, bowel problems, fatigue, psychological problems and, in its advanced stage bone pain which can have a significant impact on men's quality of life [Harvard Medical School, 2018].

Prostate cancer is the second most common cancer in men [Siegel, Miller, & Jemal, 2015] and the seventh leading cause of death internationally, with lung cancer being the highest cause of death worldwide [World Cancer Research Fund International (WCRFI), 2016]. Men aged 50 or over are considered to be at risk of developing prostate cancer, as are men with a close relative, such as a brother or father, who have been diagnosed with prostate cancer [Cancer Research UK, 2018]. There is some evidence suggesting that a diet high in animal fats may increase the risk of developing prostate cancer [Macmillan Cancer Support, 2015]. Moreover, several studies have highlighted that obesity and a lack of exercise are risk factors and these play a pivotal role in the development of prostate cancer [WCRFI 2016; Chung *et al.*, 2019; Er *et al.*, 2017].

In Western countries, approximately 68% of prostate cancer cases are diagnosed in more developed countries [WCRFI, 2016]. The rates are highest in Australia/New Zealand and North America, and in Western and Northern Europe because of the practice and frequent use of prostate specific antigen [PSA] testing and subsequent biopsy that are used within these regions [Globocan, 2018; Bray *et al.*, 2018]. The lowest rates of prostate cancer incidence can be found in South East Asia [Chen *et al.*, 2014]. Asian men have a lower risk of developing prostate cancer whilst other ethnicities, particularly black men are at a greater risk of developing prostate cancer. The reason for this ethnic disparity is currently unknown [Thompson, 2014]. In the United States of America [USA], African-American men have higher mortality rates [American Cancer Society, 2019] with the survival gap wider than any other race or ethnicity [Aizer *et al.*, 2014].

Men of African-Caribbean origin have higher prevalence, incidence, and mortality rates of prostate cancer [Patrick *et al.*, 2015]. In the UK, research has shown that black men of African and Caribbean heritage are two to three times more likely to be diagnosed with

prostate cancer compared with white men [Ben-Shlomo *et al.*, 2008; Nanton and Dale, 2011] and they have a worse prognosis in comparison with their white UK counterparts [Evans *et al.*, 2008]. Moreover, data showed that black men of African and Caribbean backgrounds were more likely to be diagnosed with prostate cancer at a younger age than white men; on average, 67.9 years for black men compared to 73.3 years for white men, and once a diagnosis of prostate cancer is made, black men are found to have a more advanced stage of the disease [Ben-Shlomo *et al.*, 2008; Prostate Cancer UK 2017b].

In the UK, Nanton and Dale [2011] carried out a qualitative study exploring 16 African and Caribbean men who had been treated for prostate cancer. The study revealed that black men had poor awareness of prostate cancer, had a lack of knowledge of what the prostate did and where it was in the body. Additionally, the study revealed that black men felt they had a lack of information regarding prostate cancer and they criticised health professionals for not being made aware of the side effects of treatment [Nanton and Dale 2011]. Equally, a qualitative study conducted by Anderson *et al* [2013] used seven African and Caribbean participants aimed at capturing their experiences and understanding of prostate cancer and its associated risks. Participants indicated that both health education and information regarding prostate cancer were lacking from the outset and this prevented them from gaining a better understanding of the disease and the side effects of treatment. It is clear from both studies that a more proactive approach to giving and providing information is needed. Such findings are similar to Cremin's [2015] work which is based on black and minority men with prostate cancer. Some studies have examined black men's experiences of prostate cancer [Alexis, 2019; Anderson *et al.*, 2013] and the impact of the disease on their sense of masculinity [Alexis and Worsley, 2018a]. This study will report the findings of a qualitative study that has as its focus, black African and black Caribbean men's experiences post prostate cancer treatment in England.

### **Aims of the study**

To examine black African and black Caribbean men's experiences post prostate cancer treatment in England and to create a video to raise awareness in the African and Caribbean communities of the importance of getting tested for prostate cancer.

### **Method**

Qualitative research involves the systematic collection, organisation and interpretation of textual data derived from a dialogue between the researcher and the participant[s] [Mason, 2018]. Using a qualitative paradigm to explore the aims of the study would provide invaluable insights on black men's experiences in England. Qualitative research involves an

interpretive naturalistic approach to the subject matter [Bryman, 2016]. This means that qualitative researchers study phenomena in their natural settings by attempting to make sense of or interpret phenomena in terms of the meaning that participants attribute to these experiences [Denzin and Lincoln, 2011].

### ***Inclusion and Exclusion Criteria***

Twenty black African and black Caribbean men who were willing to participate and were prepared to be interviewed were sought. The inclusion criteria for the study were:

- Black men aged 45 or over who were willing to participate in this study providing that they had a diagnosis of prostate cancer and had been treated for the disease.
- They identify themselves as black men of African and Caribbean backgrounds and have a current or previous medical diagnosis of prostate cancer. .
- Black men were also included if they had been in the terminal phase of the illness.
- Black men were excluded if they did not have a diagnosis of prostate cancer and were not of a black African or black Caribbean background and were not residing in the UK.

### **Data collection**

Recruitment of black men was through two processes. The first was through a voluntary African and Caribbean organisation in London, and the second was through snowball sampling. In the first process, the researcher approached the manager of the organisation to explain the study's focus and to seek support. Once full explanation was given, the manager agreed to support the project. Information sheets and consent forms were left with the manager who distributed these to prospective participants. As a result of using this process, participants made contact with the researcher to express their interest in the study. Following full explanation of the study to participants, they agreed to take part. The researcher subsequently arranged a time and place convenient for both for the purposes of interviewing them. Prior to interviewing all participants, written informed consent was obtained. The second process for recruiting participants was through snowball sampling. This involved participants passing on details of the study to other African and Caribbean prostate cancer survivors. Participants contacted the researcher and after full explanation of the study by the researcher they agreed to take part. Arrangements were subsequently made to interview them at a convenient time and place. Consent was obtained from all participants prior to interviewing them.

All face-to-face interviews lasted approximately 1 hour and were recorded using a recording software called Audacity. These interviews were conducted by the researcher and they were fully transcribed by an external transcriber. The semi-structured interviews used the following questions: Could you tell me a bit about what you know about prostate cancer? Could you tell me how prostate cancer has affected your life? Could you tell me a bit about your treatment to date?

For this study Nelson's [2016] conceptual depth approach was used and it is defined as achieving in-depth understanding of the phenomenon under investigation. Nelson's [2016] has identified some measures which researchers' studies could be judged against in determining their depth. These criteria are identified below:

- A wide range of evidence can be drawn from the data to illustrate the concepts.
- The concepts must be demonstrably part of a rich network of concepts and themes in the data within which there are complex connections.
- Subtlety in concepts is understood by the researcher and used constructively to articulate the richness in its meaning.
- The concepts have resonance with existing literature in the area being investigated.
- The concepts, as part of a wider analytic story stand up to scrutiny.

Using the above criteria, this current study met these criteria. Moreover, using 20 participants were deemed to be sufficient to provide in-depth information of the phenomenon under investigation [Nelson 2016].

## **Analysis**

The transcripts were analyzed using Braun and Clarke's [2006] thematic framework. This process involved becoming familiar with the data by listening to the recorded interviews and rereading verbatim transcripts which were imported into a Qualitative Research Software [QSR] NVivo 12 package [QSR International, 2016]. The researcher then generated initial codes and then searched for sub-themes. These sub-themes were reviewed and clustered into organizing themes. The next stage involved the aggregating of organizing themes into global themes. The final process was writing up these themes into a report. During the analytical process, notes were kept using a reflective diary and these notes were used to inform themes.

## **Ethical considerations**

Ethical approval was given through a local university in the UK and the study was guided by the code of practice approved by the ethics committee at the local university. Data were anonymised and stored in accordance with data protection requirements [Data Protection

Act 2018]. Both physical and electronic data were stored in a locked cabinet including consent forms. Audacity recordings were stored on the researcher's Google Drive of which the researcher alone had access to. Full explanation regarding anonymity was given to black African and black Caribbean men in terms of maintaining confidentiality in any research outputs. All data collection storage and process complied with the principles of the Data Protection Act [2018] and the EU directive 95/46 on data protection.

## **Findings**

Twenty black men participated in the study. The sample comprised 3 black men with ancestral backgrounds in Africa, with 17 black men either born in the Caribbean, or their parents being originally from the Caribbean. Of the 17 black Caribbean men, 12 were from a Jamaican background, including 3 gay black men, and 5 were from different Caribbean countries. Sixteen participants were aged 48 to 57 and four were above age 57. The different treatment options were hormonal therapy, radiotherapy, radical prostatectomy, active surveillance, brachytherapy, and robotic therapy. A number of themes were found but the following themes will be reported on for this publication: black men's knowledge and understanding of prostate cancer, mis-information, herbal remedies, information needs and unconscious bias.

### ***Black men's knowledge and understanding of prostate cancer***

Black African and black Caribbean men stated that they knew nothing about prostate cancer and its effects on them. The following extract highlights their perspectives regarding prostate cancer:

*I never knew and understood what the prostate was, I mean, you know, the meaning of prostate and what it does and what it doesn't do, because it wasn't something that I looked up or read [Interview Male 6].*

Another stated, he knew it was a form of cancer but how it affected other people and what may have triggered it was something he was unaware of:

*But I didn't really know much about prostate itself, I didn't really delve into what it actually did. I knew it was a form of cancer but how it affected you, how it affected other people, where it came from, how it came about the kind of things that might have activated it or triggered it, I didn't know [Interview Male 11].*

Not knowing about prostate cancer was an emergent theme throughout all black men stories:

*Well not a lot. I didn't know much about it when I became ill, I didn't know anything about prostate cancer because I never actually heard anyone talk about it [Interview Male 14].*

### **Misinformation**

Some black men shared their experiences in relation to misinformation they received from other members of the black community regarding a cure for prostate cancer. They stated that an elder in the black community has the cure for prostate cancer.

*She said that she knows an elder who has the cure for cancer. At that point I sat up tight to find out who this great man was. And you've got to ask yourself, how often does this sort of information gets to the black community [Interview Male 2].*

*You know people are very guilty of jumping to the wrong ideas when it comes to the test for prostate cancer. They have told me so many different things about the test which was untrue [Interview Male 20].*

### **Herbal remedies**

Some black men had considered or used herbal remedies to eradicate prostate cancer. Such information was obtained through using the internet or through recommendation from other black men. Some indicated that, had they known about these remedies they would have tried them instead of surgery.

*Yes, I would have tried herbal remedy. I've heard so much, you know, you've got in the Caribbean at the moment, Moringa, yes, Moringa, it, allegedly, it's supposed to be very, scientifically proven, it's not something that can be scoffed at, it's scientifically proven, because I've read up a lot on it on You Tube. I have taken some of it. You know, things like, there's certain things like, they say, Cassava, seems to be very good, things like Green Tea. I've tried the Cassava [Interview Male 13].*

Another stated that:

*One of my friends knows about this problem, and said, his uncle had something like that and he bought some herbal medicine back home. And he used it and he was cleared of this thing. I thought about it, and said if I'm going to have a test, some blood test, would I be OK [Interview Male 5].*

### **Information Needs and Unconscious bias**

Information giving is an important aspect of healthcare delivery and for the majority of black men this was not apparent. They wanted as much information as possible for the benefit of allaying their fears and anxieties but also for knowing what to expect. Some black men of African and Caribbean backgrounds perceived that their racial features were a barrier in the way in which limited information was shared with them by health care professionals:

*So that's what I was interested in and they said, OK, look into Cryotherapy. So look at it, this is still in the early stages, but consider it and come back and let us know if that's what you really want. But they didn't explain to me at that point, that Cryotherapy could only be done on one side of the prostate and I was diagnosed on both sides of*

*the prostate. So I looked at it and I went back to them and I said, yes, I've decided, I want to do Cryotherapy. Then they said, well you can't do Cryotherapy because it's on both sides. So I said, why didn't you say that before? So I went back to them and said, OK, I've decided on radiation. And then they said, radiation is OK but you should bear in mind that it could cause other cancers later in life. So I said to them, OK, what it means then, is that the only option for me is surgery, because I'm not going to go for radiation if there's a possibility of other cancers. So I said, I wish all of this had been said, so that would have helped me to make the decision so much faster. So the information was a bit iffy. I think it could have been a little bit more precise, in terms of my own personal needs [Interview Male 10].*

Another stated:

*The doctor said he couldn't see anything. But then they still said to me, we're going to send you for a biopsy. So they sent me for the biopsy, I'm like, what's this about? Again, it was almost like they were hiding something from me. And I would rather have known up front, where we're going with this and for what reasons why they keep on pushing me to the next stage of the test, because if you've scanned and they haven't seen anything and if he said, the prostate wasn't enlarged, I just don't, I still don't know to this day, what triggered it. And there was no other discussion about anything none whatsoever. I just don't know why they have not given me much information. Is it because I am a black man that I don't need information? What is it really? [Interview Male 11].*

Another stated that, he left the hospital with no culturally-specific literature to read and would have liked some information on what to expect and what preparation he should make for his impending surgery:

*So I walked out the door, knowing that I've got prostate cancer, but without having any kind of literature to go home to read up about or to see if, or to direct me to people or websites that I can actually go on and receive or get the information. I walked out the door without a leaflet or some kind of culturally-specific information [Interview Male 7].*

Although some black men felt that information was not always available, others felt that they were given information as illustrated in the below extract:

*And he gave me a leaflet on a new thing that the NHS was rolling out and would I consider it? And they sent me a lot of leaflets regarding the procedure and what it was about [Interview Male 13].*

## **Discussion**

This study found that black men lacked understanding and knowledge about prostate cancer. They were not aware that prostate cancer affected black men disproportionately to that of their white counterparts. The findings described in this study are consistent with previous studies that featured descriptions of black men's poor awareness and lack of knowledge of prostate cancer [Pedersen *et al.*, 2012; Anderson *et al.*, 2013; Cremin, 2015; Alexis and Worsley, 2018b]. Equally, studies drawn from the United States of America [USA]

reported that black men lacked knowledge and education on prostate cancer and this led to misconceptions about the disease [Forrester-Anderson, 2005; Ford *et al.*, 2006].

Black men spoke of their experiences of obtaining misinformation pertaining to a cure for prostate cancer. Although this was a minority of black men, clearly such misinformation is pervading the black community and therefore this could have influenced some black men's decision as to whether they should or should not seek medical advice for their condition. Added to this was the notion of herbal remedies which some black men said was touted as a cure for prostate cancer. Some indicated that they would have tried these remedies had they know about them, whilst others felt that they needed to be scientifically tested before using them. Evidence drawn from Nanton and Dale's [2011] work reported that there was a belief that some black men would use herbal remedies to complement their medical treatment for prostate cancer and therefore the findings of this study are consistent with Nanton and Dale's [2011] research.

In this research some black men pointed out that they needed more literature that would specifically address their cultural needs, treatment options and general information regarding the prostate cancer journey. This was a strong emergent theme in this study. This finding confirmed similar studies that examined the information needs of prostate cancer survivors in both black men and white men [Paterson *et al.*, 2015; Zhou *et al.*, 2016; Bobridge *et al.*, 2015]. Moreover, proponents such as Anderson *et al* [2013] postulated that providing information to men of African and Caribbean backgrounds specifically about prostate cancer and its associated risks could positively impact on them. Given the importance of information and the impact it could have on the wellbeing of black men throughout the prostate cancer journey, a minority of black men reported that they felt that information was unconsciously withheld. Given that positive changes in racial attitudes have occurred in the NHS in England [Kline, 2015], research also revealed that implicit bias was one of the ways in which racial bias manifested itself but made it less recognisable. In navigating their social world, healthcare professionals might engage in conscious, deliberate cognitive processes as well as implicit [unconscious] automatic evaluative processes based on images stored in their memory [Williams & Wyatt, 2015]. Therefore, storing negative beliefs about black men would be deeply ingrained in their unconscious memory leading to healthcare staff exhibiting behaviours which were considered by some black men to be contrary to what would be expected of healthcare professionals.

### **Limitations of the study**

This study provides a deep understanding of the experiences of black men with prostate cancer. This is a retrospective study and it relied on black African and black Caribbean men's recollection of their experiences, and therefore the accuracy of their recall may have been distorted due to the passing of time. Nonetheless, the stories that black men offered regarding their experiences were insightful, informative and invaluable and should not be relegated to insignificance. Moreover, this study was conducted by one researcher and the interviews were analysed by the sole researcher and this is another limitation of the study.

### **Conclusion**

Black men in this study lacked awareness and understanding about their increased risk of developing prostate cancer. This has seen misinformation disseminate throughout the Black communities. Particularly, there is misinformation about a supposed cure for prostate cancer. Herbal remedies were touted through word-of-mouth and unsubstantiated internet sources as a means of curing prostate cancer. Some black men questioned the likelihood of a cure and wanted information from health professionals to alleviate their fears and anxieties. However, a minority of black men reported perceived implicit bias from health professionals, and that information was not tailored to their own cultural or individual circumstances. To stem the flow of misinformation, literature should be adapted to consider the specific needs of black men and to challenge spurious claims. This [video](#) depicts one black man's battle with prostate cancer, his feelings towards testing, black men's information requirements, and the need to encourage other black men to get tested for prostate cancer. This video may aid in assisting healthcare professionals to raise awareness of prostate cancer in Black communities.

### **Why you should read this article**

- To gain an understanding into black men's experiences of prostate cancer
- To highlight that black men require knowledge and information pertaining to prostate cancer
- To gain insights into the views and experiences of black African and black Caribbean men
- To become more aware of prostate cancer in black men

**Prostate Cancer Awareness Video link:**  
<https://www.youtube.com/watch?v=mxgVhDcza6E&t=3s>

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**Ethical approval:** All procedures performed involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

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